

SPINAL COURIER

SPINAL CORD

Vol. 5 No. 4

July, 1994



Dr. Stevenson Flanigan and his wife, Sue, admire the plaque he received in appreciation of his many years of service to the Commission

"SEEKING OPPORTUNITIES" 1994

"Great!" "An excellent conference." "Very interesting and informative." These are comments from the evaluations of ASCC's Fifth Annual "Living with Spinal Cord Injuries in the '90s" conference on May 20, 1994, at the C.A. Vines Arkansas 4-H Center in Ferndale. Almost 250 clients, family members, professionals, speakers and staff attended ASCC's latest and most successful conference.

Highlights of the conference included Keynote Speaker Aric

Fine of the 1996 Paralympic Games talking about seeking opportunities and Dr. Stevenson Flanigan describing the growth and changes in SCI care and treatment in Arkansas from 1967 to 1994. In addition, Dr. Alex Finkbeiner's discussion of recent advances in Urology was very well received.

Dyann Beasley, VISTA volunteer at Arkansas Disability Coalition, had a pleasant surprise at the close of the conference. She was the See 1994 Conference - Page 5

MARK YOUR CALENDAR

Friday, September 23, 1994, plan to be at DeGray State Park for our Outdoor Recreation Extravaganza. If you love the outdoors, like the outdoors or think you might, you need to join us for this experience. Skip Wilkins of Virginia Beach, VA who is an avid outdoorsman, fisherman, boating enthusiast and motivational speaker (and also a quadriplegic) will be with us that day to set the tone and demonstrate his expertise. If you missed Skip when he was here before, you need to hear him this time.

In addition, there will be lots of outdoor fun, including a barbecue lunch, demonstrations of Quickie Outdoor Recreation Equipment (including the waterski for people with disabilities, hand-pedal bike and racer), barge rides, a nature talk and, of course, fishing.

Hot Springs Case Manager Bettie Tapp has coordinated this event for the past five years for folks in her region (ask anyone who's been - it's great) and this year she's letting us expand to invite all Arkansans with spinal cord disabilities. This is a great opportunity to bring your family and learn about new outdoor opportunities. You will be receiving additional information about the event in mid-August with maps and registration materials - but mark September 23 on your calendar now and be there! See Skip Wilkins - Page 8

ASCC GETS NEW PHONE NUMBERS



The Arkansas Spinal Cord Commission Little Rock offices phone numbers have been changed effective 6/28/94 to the following:

	<u>Old #</u>	<u>New #</u>
Administrative	324-9624	296-1788
Executive Director	324-9626	296-1790
Case Management	324-9628	296-1792
Research and Prevention	324-9620	296-1784
FAX#	324-9623	296-1787
TDD#	324-9630	296-1794

SPINAL COURIER

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Cheryl L. Vines Executive Director

Thomas L. Farley Editor

The Arkansas Spinal Cord Commission does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

BUCKLE UP!

THANKS FOR THE SECONDARY CONDITIONS SURVEYS

The Secondary Conditions Surveys have been steadily returning and have a lot of very useful information. Thanks for the time, effort and thoughtfulness displayed by those of you participating in this study. Although only a small number of clients were surveyed, the information from this limited survey should prove to be very valuable.

You'll probably be hearing more from us later as we try to identify and prevent those things that keep individuals with spinal cord injuries from achieving their full potential. Thanks again for your help!

FOR YOUR INFORMATION

Seat belts, child restraint equipment, airbags or helmets were **not in use** in **over 65%** of all motor vehicle crash related spinal cord injuries in Arkansas from 1990-93.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

LET THE GOOD TIMES ROLL!

Dear Editor:

"LAISSEZ LES BON TEMPS ROULEZ" (Let the Good Times Roll) is the theme of this year's National Spinal Cord Injury Association Convention being hosted by the Louisiana Chapter in New Orleans September 9-13, 1994.

The convention will provide a forum for the exchange of information and new developments. Topics will include new concepts and innovations in methods of treatment, techniques and research. The effects of SCI on individuals in all spheres of life, including interpersonal, recreational, spiritual and vocational will be explored.

There will be many recreational activities and opportunities to enjoy New Orleans. So, y'all come on down and join us and LAISSEZ LES BON TEMPS ROULEZ!

For additional information call Yadi Mark at 504-454-1178, or Kara Hoerner at 504-522-1955.

Yadi Mark, Pres. Elect LA Chapter, NSCIA

WHEELCHAIR RACING - GIVE IT A TRY!

Dear Editor:

Marty Johnson, who has been racing competitively for several years, invites anyone interested to come "give it a try." He has offered his services to help train persons (children and adults). There may be opportunities for those who excel to get official racing wheelchairs. Call Marty at 851-3252 or Joe McNeil in Hot Springs at 777-5776.

Martha Henderson ASCC Case Manager



FILL 'ER UP, PLEASE!

Dear Editor:

As a former resident of Texas, I know of a law in that state (and possibly in other states) that service stations providing full service must provide this service to physically disabled persons at self-serve rates since they do not have the choice of using self-service. It has been my personal experience that some service stations in Arkansas voluntarily provide this service even though there is no such law here.

Readers of Spinal Courier might ask the managers of the service stations where they frequently fillup their gas tanks whether or not they would be willing to sell full service gasoline at the self-serve rates.

Karen Schmidt Vilonia, AR

HIGH PROFILE!

ANNIE MC KNIGHT

This is the third in a series of articles profiling the ASCC Case Managers.

Being a "people person" is one attribute Annie McKnight has used effectively during her 26 year tenure in state government. According to Annie, "If you enjoy challenge and love helping people, the rest will fall in place." And apparently, it has because her love for people has made Annie a very persistent advocate for those individuals she serves. Many client service providers, vendors, and other state agencies in Southwest Arkansas will certainly testify to her determination when it comes to obtaining services and resources.

Annie's early background in teaching and as an employment counselor eventually led her to case management. After obtaining her Masters in Counseling from Arkansas State University in Jonesboro she continued to work for the Employment Security Division for several years before joining the Spinal Cord Commission team in 1984.

Located in the Magnolia office, Annie covers the counties in the Southwestern part of the state. Putting in a lot of "windshield time" all these years hasn't diminished her enjoyment of traveling. "You meet a lot of interesting people throughout the course of the day." Annie loves helping other people in whatever way she can, and she believes, "the satisfaction is knowing you have added a little comfort to their lives." One of Annie's favorite quotes from author Og Mandino summarizes her feelings: "I will persist until I succeed. I was not delivered into this world into defeat. Nor does failure course in my veins."



THREE WORDS TO DESCRIBE YOURSELF:

Fun, Intelligent, Great personality!

FAVORITE PASTIME: Playing tennis.

BEST WAY YOU UNWIND: Traveling.

PERSON YOU ADMIRE THE MOST:

My father - he was the greatest influence on my life.

FAVORITE AUTHOR:

Og Mandino. I just read his book, The Greatest Salesman in the World.

DREAM VACATION:

Switzerland - I've always wanted to see the Alps.

TALENT YOU'RE PROUD OF:

Writing poetry. Someday, I want to have my poems published.

ANYTHING ABOUT YOURSELF YOU'D CHANGE:

My knack for getting lost. I'm a "Directional Dyslexic."

ADVICE FOR A PERSON WITH A DISABILITY:

Work hard and learn to deal with the changes in your life.

WHY CASE MANAGEMENT:

It's exciting and everything I had previously done led up to Case Management. But mainly, it was my love for people.

MOST IMPORTANT THING YOU'VE LEARNED AS A CASE MANAGER:

The ability to relate effectively to different personalities.

ANOTHER GREAT CAMP

1994 was another great year for Spina Bifida Camp! Sixty-eight kids enjoyed a week of fun at Camp Aldersgate. Activities included swimming, crafts, field trips, music and an overnight camp-out. The Rollin' Razorbacks put on an exhibition the first week of camp, and a Fourth of July Parade (complete with golf cart floats) highlighted week two.

Spina Bifida Camp is sponsored by the Arkansas Spinal Cord Commission, in cooperation with MedCamps of Arkansas. Once again this year, many organizations showed their support for Camp by serving as Cosponsors. We couldn't have done it without them and want to show our appreciation by letting everyone know who they are.

A BIG THANKS TO:

Horton Orthotics Lab Arkansas Spinal Cord Injury Association United Medical, Inc. Jonesboro Rotary Club John Haskins Kiwanis Club of West Little Rock Children's Medical Services
Spinal Bifida Association of AR
Whitewood Shrine Club
Kiwanis Club of North Little Rock
Northeast Arkansas Rehabilitation
Hospital
Kiwanis Club of Greater Hot
Springs Village

NEW VIDEOS AVAILABLE!

The Arkansas Education and Resource Center on Spinal Cord Injury has several new videos now available.

- Deer Hunters and the Outdoor Sportsman is a 60 minute tape of Arkansan Larry Wilson of Bald Knob demonstrating how to transfer onto a four-wheeler, getting in and out of a boat, assembling a tent, and getting in and out of a deer stand he made. (This video was filmed by ASCC Case Managers John Baker and Martha Henderson great job!).
- Breezy Board is a 16 minute video about the new transfer board and a demonstration of how it works.
- Sexuality Reborn is a 48 minute video produced by the Kessler Institute about sexual relationships between persons with SCI.
- Advances in Urology is a 60 minute tape of Dr. Alex Finkbein-

er's session at the 1994 fifth annual ASCC "Living with Spinal Cord Injuries in the '90s" conference.

• Wheelchair Seating is a two hour tape of the class held at the 1994 fifth annual ASCC conference featuring Eric Strader, Rehab Engineer from Baylor Institute for Rehabilitation, Dallas, TX.

SKIP WILKINS

Continued from Page 1

Skip Wilkins will also be making a presentation on Thursday, September 22, 1994, at 7:00 p.m. at the Calvary Family Life Center on N. Pierce & R St. in Little Rock as the guest of the Oasis Renewal Center Physical Disabilities Support Group. You are welcome to hear Skip speak then too.

LIFELINE REDUCES PHONE RATES

Southwestern Bell Telephone has two special programs - Lifeline and Link-Up - that can help seniors save on telephone services.

You are eligible if you or a member of your household are currently receiving Supplemental Security Income (SSI), food stamps, AFDC assistance or you are on the Medicaid program.

Lifeline is Southwestern Bell's reduced-rate residential telephone service. The monthly rate is about one-third the price of regular one-party service. The following is a comparison of regular one-party residential rates and Lifeline rates in the Little Rock area:

- Standard One-Party Service \$19.81 per month with unlimited outgoing local calls.
- Lifeline Service \$6.31 monthly with an unlimited number of free incoming calls and 30 free outgoing calls each month. For more than 30 calls, customers are billed at between 2.5 and 4 cents per minute for the first minute and between 1.5 and 2.5 cents for each additional minute. Charges vary based on the distance of each call.

The Link-Up Program, which provides a 50% reduction on telephone installations, was designed to reduce the burden of installation charges for low-income families and individuals. This service coupled with Lifeline provides lower cost telephone service to those who otherwise could not afford to have a phone in their homes.

To sign up for Lifeline or Link-Up contact you local Southwestern Bell Telephone Office.

Reprinted from Aging Arkansas.

1994 Conference -

Continued from Page 1

winner of a \$100 gift certificate door prize donated by Harvest Foods. Congratulations! Several of the exhibitors also had drawings for prizes that included items such as golf shirts, t-shirts, and other "fun" things.

If you missed this year's conference, make plans now to attend the 1995 conference on Saturday, June 3rd, at the Ferndale 4-H Center. You're sure to have a great day, meet new people and learn a lot.



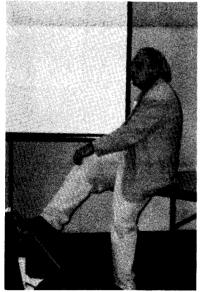
Bob Swiney of Quickie Designs, Cheryl Vines, ASCC Executive Director, Aric Fine and Horace Love, ASCC VISTA volunteer talk about Atlanta '96.



ASCC Case Manager Martha Henderson explains how SCI affects the entire family.



Aric Fine, 1994 conference keynote speaker, serves as the Assistant Director of Telecommunications for the Atlanta Paralympic Organizing Committee.



Dr. Alex Finkbeiner talks about recent advances in Urology.



ASCC Clients Danny Wooden and Mattie Jones discuss how computer networking is a great way to reach out and interact with the larger world around all of us.

ANTIBIOTIC RESISTANCE

by Shirley McCluer, M.D.

Prior to 1940, the life expectancy for people with spinal cord injuries was about two years. Deaths were mostly due to infection, especially urinary and pressure sore infections. With the development of antibiotics to treat infections, the life expectancy has improved dramatically, and is now only slightly less than the general population. Antibiotics were called "miracle drugs." In the fifty years since WWII, the antibiotic industry has grown rapidly and now over 40 million pounds are produced per year.

Bacteria perform many useful functions and are a necessary part of our environment. Only a small percent of the known bacteria have the ability to cause disease in humans. Therefore, we do not want to kill all bacteria (even if we could), only the disease-causing ones.

As newer and more powerful antibiotics were developed, we became so confident of our ability to treat infections that diseases due to bacteria were no longer considered to be a serious problem. In fact, in 1969 the Surgeon General of the U.S. said, "the time has come to close the books on infectious disease" and concentrate on other problems such as cancer, genetic defects, immune disorders, etc. Unfortunately, this optimism was premature.

In the April 24, 1994, issue of the Arkansas Democrat-Gazette there was an excellent article entitled, "Are We Losing the War Against the Microbes?" which some of you may have read. The article called attention to the fact that bacteria are becoming resistant to antibiotics faster than new ones can be developed. Infections due to simple "staph" or streptococcus are once again becoming life threatening diseases because the bacteria have developed a resis-

tance to all known antibiotics. This is especially true for infections acquired in a hospital where the more powerful antibiotics are likely to be used, but when patients with these bacteria are discharged from the hospital, they carry the bacteria to their community. Even visitors to the hospital can carry the bacteria from one person to another. Because of resistance to antibiotics, patients are once again dying from diseases such as pneumonia, TB, gonorrhea, and syphilis which a few vears ago we thought would soon be eliminated.

Although the ability for some bacteria to develop resistance to antibiotics was recognized very early, there was a feeling that newer and more powerful antibiotics would always be available. However, bacteria are now becoming resistant to multiple antibiotics much faster than new ones can be discovered and tested. It takes about ten years from the time a new drug is found to the time it is on the market. There used to be a period of about seven years of clinical use before problems with resistance occurred. Now it can happen within only two years! This makes it very difficult for a drug company to recover the costs of research to find new drugs.

Anyone who is interested in reading the fascinating description of how the bacteria are able to become resistant should read, "The Antibiotic Paradox - How Miracle Drugs are Destroying the Miracle" by S.B. Levy which is in the ASCC Resource Library.

WHY IS THIS HAPPENING?
There are numerous reasons, some of which are:

• Overuse of antibiotics -The use of antibiotics for trivial illnesses and for viral infections is probably the most important



reason for the rapid spread of resistant bacteria. The general public tends to believe that "antibiotic" means a drug that will cure all diseases. Patients often insist that antibiotics be prescribed for minor infections that could easily be treated with other methods. Virus diseases, such as colds and flu, do not respond to antibiotics and they should not be used.

Many of the resistant bacteria are coming to the U.S. from countries where the sale of drugs is not regulated and individuals treat themselves inappropriately.

- Animal use About one-half of the antibiotics used in the U.S. today are fed to poultry and livestock, not to fight disease, but to stimulate growth! (The reason this works is not understood.) Also, antibiotics are used freely to treat diseases in pets, farm animals, and even plants. In a survey of Boston groceries, drug-resistant bacteria were found on many produce items.
- Inadequate treatment It is very common for patients to stop taking medication as soon as they start to feel better, rather than take it for the full time prescribed. Although the patient may get well, the bacteria are much more likely to become resistant than if treatment had See Antibiotics Resistance Page 7

ANTIBIOTIC RESISTANCE

Continued from Page 6

continued for the prescribed time. This also leaves unused medication which can be misused at a later date or by another family member.

• Self Medication - Left over medications are often taken for inappropriate illnesses or for inadequate lengths of time. It is a good idea to discard any leftover drugs immediately to prevent this. Although antibiotics are expensive, this is **not** a good way to save money!

WHAT CAN YOU DO TO SLOW THIS PROCESS OF ANTIBIOTIC RESISTANCE?

- · Never self-medicate!
- Never insist on an antibiotic if your doctor says you don't need one!
- If an antibiotic is ordered, take it exactly as prescribed for the full length of time, not just until you start to feel better.
- Never take antibiotics that were prescribed for someone else.
- When an antibiotic is indicated, use the least powerful drug that is effective. Save the stronger ones for more serious situations.

Additional reading available from the Arkansas Spinal Cord Commission:

- The AR Democrat-Gazette article, April 24, 1994.
- The Antibiotic Paradox -How Miracle Drugs are Destroying the Miracle by S.B. Levy, 1992.

DID YOU KNOW?...

Over one-third of all women in Arkansas with violencerelated spinal cord injuries were injured by a relative; and of these, 80% were injured by their husbands.

REMEMBERING AN EXTRAORDINARY, TYPICAL GUY

Larry Whittle died last month. Larry lived 52 years, 33 of them as a quad. He was a typical guy, grew up in Blytheville, graduated from high school and went to work. His spinal cord injury was pretty typical too: 19 years old, driving late at night, fell asleep, went off the road, car rolled and Larry broke his neck. The fact that he survived that experience in rural Arkansas in 1961 was very extraordinary, and "typical" Larry became "extraordinary" Larry. Extraordinary because not many quads in 1961 survived, even less went to Hot Springs Rehab Center, and very few returned to work (as a dispatcher for the Arkansas Highway Department). But Larry did all of that.

I knew about Larry long before I ever met him. I had read and heard his name as I learned about the beginnings of our Commission. It was men like Larry and Harold Thomas and Lynn Norton that helped Jane Smith convince the Arkansas Legislature that we needed a Spinal Cord Commission.

I thought Larry was pretty extraordinary the first time I met him on a hot summer day in 1989 in a nursing home in Blytheville. Larry had moved there some years previously when his mom could no longer care for him. I was amazed that day because the hubbub of the seniors in the nursing home didn't seem to bother Larry at all; in fact, he seemed to be directing things. In a situation that seemed dreary (really depressing) to me, he seemed to be happy and doing well.

The next time I saw Larry he really was happy and doing well. He'd gotten married to Barbara (a long-lost high school friend), was living in Arkadelphia, being a stepdad and preparing to return to work. He was driving again and seemed to be enjoying his life. They'd come to our first conference and started talking to me about the topic of aging with a spinal cord injury - where could they find info? There wasn't much to tell them then. Three years later knowledge on aging and SCI is just beginning - but, unfortunately, too late for Larry.

Larry Whittle died last month, his quad body finally gave out. Thirty-three years of UTIs, pressure sores, skin flaps, osteo, chronic pain, respiratory problems and finally hyponatremia took their toll.

It seems so ironic. This typical, extraordinary guy finally found real happiness and his body gave out. Sure there's the other side of the story. Larry smoked too many cigarettes, maybe had a few too many drinks at one time, and saw so many different physicians over his lifetime that no one knew what the other had done. He took so many antibiotics that eventually none of them worked.

Is there a moral to my story? Yes, there are two. First, we've lost a great friend without whom our Commission might not have come into being. Second, we need to learn from this tragic experience. Larry became a quad before we knew about things like follow up clinics, annual urological tests, roho cushions and aging. By the time he learned, a lot of the damage was already done. We can learn from Larry's life. We know now what works, but if you wait to use it, it may be too late. We only get one body, take good care of it. Don't depend on someone else to do it it won't happen.

Larry Whittle died last month, I'll miss him.

Cheryl Vines

BE A PART OF THE SOLUTION!

If you're not satisfied with things as they are and you're not doing anything about it - then you're part of the problem. If you're trying to make a change, then you're part of the solution. Members of the AR Spinal Cord Injury Assn. (ASCIA) are people who are working to make things better for people with disabilities, especially those with spinal cord injuries (SCI).

ASCIA has:

 Influenced legislators to change and make laws that help people with disabilities;

- Surveyed polling places and public schools for accessibility;
- Raised money for an annual scholarship fund (five \$500 scholarships are awarded to students with SCI);
- Began the "Polaroid Patrol"
 which allows private citizens
 the right to take photos of vehicles illegally parked in disabled
 parking zones, resulting in war
 rants issued to the owners of
 such illegally parked vehicles
 by the Little Rock Police Dept.

These are just a few changes brought about through the efforts of ASCIA. There are many other changes that need to happen, and ASCIA needs YOU! Quit complaining and be a part of the solution - become a member of ASCIA.

ASCIA meets on the first Tuesday of each month at 6:30 p.m. at Baptist Rehab Institute in Meeting Rooms 2 and 3 in the basement at ground level, adjacent to the Social Work Department. Our next meeting will be Sept. 13th. Call 568-6406 for more information. Come on! Join us and be a part of the solution.

WITH THANKS

The Arkansas Spinal Cord Commission accepts tax deductible donations. We appreciate the many individuals and families over the years who have made the Commission recipient of memorial donations. Contributions are used to assist our clients through purchases of equipment and educational resources. If you would like to make a contribution, please contact the Commission or send your donation to ASCC, 1501 N.

University, Ste. 470, Little Rock, AR 72207.

Recently the following individuals made greatly appreciated contributions:

In Memory of Larry Whittle
Barbara Whittle
Staff of the Department of Physical
Medicine and Rehabilitation,
Veterans Administration Medical
Center,
Freda Kelly
Alice O'Kennon

CALENDAR OF UPCOMING EVENTS

National Spinal Cord Injury Association (NSCIA) convention, "Laissez Les Bon Temps Roulez," in New Orleans, LA, September 9-13, 1994. For additional information, call Yadi Mark at 504-454-1178, or Kara Hoerner at 504-522-1955.

To have activities announced in the upcoming issue of Spinal Courier, call the Editor at 324-9620 by 10/3/94 for the October issue.

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SPINAL COURIER

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